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Becoming incapacitated? Long-term sickness benefits recipients and the construction of stigma and identity narratives

Abstract

The transition to becoming 'incapacitated' and receiving sickness benefits represents a significant shift in one's narrative. Drawing on in-depth interviews with 25 long-term sickness benefits recipients in North East England, UK, this paper focuses upon how individuals perceived and managed becoming 'incapacitated', particularly in relation to stigma and identity. Findings show that participants negotiated changes to their identity in varying ways - constructing new dimensions of self; validating their illness; and pursuing aspirations. Importantly, the transition onto sickness benefits does not inevitably result in a negative identity shift. The term 'incapacity' can include many realities, challenging the notion of sickness benefits recipients as being passively dependent. Instead, an active, sometimes very functional sense of self can be accompanied by a positive identity for recipients, which is especially important given the rhetoric surrounding ongoing welfare reform and sickness benefits recipients in the UK.

Key Words: Narrative; sickness benefits; stigma; identity; disability; welfare reform; qualitative

Word Count: 7,006

Introduction

There is a rich and plentiful sociological literature describing the biographical impact of illness - the processes that are a consequence of the changes brought about by illness, and the subsequent adaptive processes, including biographical disruption (Bury 1984), biographical reinforcement (Carricaburu and Pierret 1995; 2005), illness experience as a form of self-development and liberation, and identity (re)formation (see, for example, the work of Bury 1982; 2001; Charmaz 1983; 1987; Clark and Mishler 1992; Faircloth *et al.* 2004; Frank 1993; 2000; Hyden 1997; Radley and Billig 1996; G.H. Williams 1984; S.J. Williams 2000, amongst others). Despite such a vast and varied tradition discussing chronic illness narratives, what has been largely absent is the voice of long-term sickness benefits recipients. Additionally, a question that has remained unexplored is how individuals make sense of the transition onto sickness benefits, particularly in relation to stigma and identity. Instead, studies of people receiving sickness benefits have tended to focus largely upon the labour market and employability (Kemp and Davidson 2010) and the changing nature of sickness benefits receipt in terms of gender (Beatty *et al.* 2010). With few notable exceptions (Riach and Loretto 2009; Wainwright *et al.* 2012) the issue of self identity and sickness benefits receipt has remained somewhat overlooked. These narratives are particularly important given the ongoing welfare reform that sickness benefits recipients in the UK are currently experiencing. Through exploring the narratives of sickness benefits

recipients, a counter-narrative to the 'scrounger' discourse that is popular within the mass media, government rhetoric and public opinion can be shaped (Garthwaite 2011).

The study is particularly interested in exploring how people receiving sickness benefits construct their identity amidst political, media and public constructs of welfare 'scroungers', including the relationship between sickness benefits receipt and stigma in the narratives. Findings offer valuable insights into the lived experience of long-term sickness benefits recipients in relation to identity theory, disability studies and welfare policy.

Methods

Study context

Although it would not be viable to succinctly summarise the entirety of changes to the UK benefits system here, it is important to briefly note some key facts and figures. In November 2012, the working age early estimates of sickness benefits recipients was 2.4 million (Department for Work and Pensions [DWP] 2012a). The key sickness benefits referred to throughout are: Employment and Support Allowance (ESA) for new claimants from October 2008, and Incapacity Benefit (IB) for those claiming prior to October 2008, both of which provide support for people who cannot work because of an illness or disability. Under the ESA regime, IB recipients and new claimants must undergo the Work Capability Assessment (WCA) carried out by a private company, Atos Healthcare. Whilst it might seem obsolete to be discussing 'incapacity' when IB recipients are being moved towards other benefits such as ESA and Jobseeker's Allowance (JSA), many of the debates informing policy concerning incapacity, work and welfare remain the same, reflecting concerns over eligibility and worklessness (G.H. Williams 2010). Further reforms were declared in the Welfare Reform Act (2012b), which set out a variety of short and longer-term strategies intended to contribute to spending reductions. One example is the replacement of Disability Living Allowance (DLA), a non-means-tested, non-contributory benefit available to help with extra costs disabled people can incur, with a more rigorously tested Personal Independence Payment (PIP) in 2013. These changes have been accompanied by an increased focus upon individual characteristics and the behaviour of benefits recipients in terms of government policy and mass media rhetoric (Bambra 2008; Bambra and Smith 2010; Garthwaite 2011; Patrick 2011).

Study sample

The study employed theoretical sampling, a sampling technique used in grounded theory, which involves recruiting participants with differing experiences so as to explore multiple dimensions of the social processes under study. Qualitative semi-structured face-to-face interviews were undertaken with 25 chronically sick and disabled people (who defined themselves as either sick or disabled) receiving long-term sickness benefits in the North East of England, UK between March 2011 and August 2011. Participants involved in the research were all long-term IB recipients and were predominantly yet to undergo the WCA, so therefore had not been migrated onto other benefits such as ESA or JSA at the time of the fieldwork. All participants were initially recruited via Jobcentre Plus (JCP) 'Choices' outreach events held between September 2009 and June 2010. Of the 25 people interviewed (15 women and 10 men), a substantial range existed between the lengths of time people had spent on IB - some had been receiving it for three years, whilst others had been receiving the benefit for over 20 years. The age range of the sample varied from 32 to 65 years. Only two participants reported growing up with health problems, which were musculo-skeletal in nature. Diagnoses most frequently reported included arthritis, rheumatism, fibromyalgia, cardiovascular disease, multiple sclerosis, and mental health problems including depression and bipolar disorder. Participants were assured that all information provided would be treated with anonymity and confidentiality, and pseudonyms are used throughout. All quotations cited are in participants' own words. Ethical considerations were respected throughout the research, with the research being approved in advance by Durham University Department of Geography Ethics Committee.

Data collection and analysis

An approach based on grounded theory methodology formed the methodological foundations of the study. In grounded theory, the focus of analytical procedures is to locate relationships between concepts and themes across interviews through a process of constant comparative analysis (Charmaz, 2006; Glaser and Strauss, 1967). To elicit the narratives presented here, a semi-structured topic guide was used which included questions around: 1) experience of receiving sickness benefits; 2) health and employment histories; 3) notions of stigma and identity; and 4) perspectives on welfare reform. Here, focus is specifically upon the responses surrounding stigma and identity. Interviews typically lasted between 45 minutes to 120 minutes and were

transcribed verbatim and fully anonymised before thematic analysis was undertaken. Data analysis involved open coding and axial coding followed by narrative analysis. First, a thorough reading of each transcript was undertaken alongside NVivo 8 software to select and code quotations that referred to identity, stigma and lived experience. After coding the 25 narratives, NVivo 8 was used to connect the codes and quotations of each respondent to their story. Employing a combined analytical approach was useful for revealing the complex relationship between stigma, disability, identity development, and the ways in which participants storied their experiences of living on long-term sickness benefits. Each of the condensed stories was then read and coded for themes related to the following three categories: constructing new dimensions of self; validating illness; and pursuing aspirations.

Findings: (Re) constructing narratives of identity and stigma

The findings are presented in three sections under the over-arching theory/narrative of (re)constructing narratives of identity and stigma. Emerging as significant themes, several resources were employed to strategically protect and preserve identity - constructing new dimensions of self; validating their illness; and pursuing aspirations. These categories are especially important when considering a re-evaluation of theory and policy in relation to sickness benefits recipients; they show that sick and disabled people can create a positive stigmatised identity, confronting the idea that claimants are passively dependent.

Constructing new dimensions of self

Changes to the welfare landscape mean that consequently, individuals have to rebuild themselves and their identities. Charmaz (1983), working within a symbolic interactionist tradition, developed the concept of 'loss of self'. Similar to the findings presented here, Charmaz observed how loss of self was a multi-faceted experience for her participants who often led restricted lives, experienced social isolation, were discredited by self and others, and experienced the humiliation of being a burden on others as a result of their illness or disability (Lawton 2003). Gareth Williams (1984) introduced the concept of 'narrative reconstruction' to describe the conceptual strategies people employ following a 'biographically disruptive' event of illness onset. Thus, Williams' study highlights the ways in which narrative reconstruction can be used to '*reconstitute and*

repair ruptures between body, self, and world by linking and interpreting different aspects of biography in order to realign present and past and self and society' (1984: 197).

Becoming incapacitated?

Identities were created and recreated in line with self definitions of sickness and disability, which were interwoven with a negative, stigmatised narrative imposed upon individuals by a wider discourse. An acceptance or rejection of a disabled identity was a key theme within the narratives. Kirsty, 33, a prison officer for ten years until an accident at work left her in constant pain, struggled to negotiate a disabled identity:

I found it very difficult to accept that I had a disability cos I've always been fiercely independent. I've never asked for help before, it wasn't in my nature and to have to ask for it was tough. Trying to quantify being disabled was difficult, it was something to get your head round and I still don't think of myself as disabled, I'll still call it an injury rather than a disability.

As can be seen in Kirsty's narrative, terminology and the labels that society gives disabled people affect not only the way disabled people are perceived, but also how they perceive themselves (Zola 1993). Later in her narrative, Kirsty spoke of how she was labelled as '20% disabled' following an Industrial Injuries Disablement Benefit assessment:

You go through the medical then they decide what percentage disabled you are. They class me as 20% disabled because it's only one arm and my neck that's affected, they don't look at how much of your life is affected. Disability Living Allowance looks at how much your life is affected by your health, where Industrial Injuries looks at how much of your body is so I'm classed as 20%...when you think about it, it is weird because it's something that does severely restrict me day in, day out but to be told I'm 20% disabled...at the time I was actually really annoyed I was disabled at all.

What separates disability from sickness in the narratives presented here is whether sickness or injury was viewed as having permanence. Kirsty was keen to reject a disabled identity and disassociate herself from the 'undesired differentness' (Goffman 1963) she believed came with being disabled – a loss of independence, reliance on others for help, and ultimately a permanence to her condition; a convergence with one facet of

statutory definitions. Kirsty's experiences show the dominance of such a medicalised perspective; here, Kirsty was struggling with the administrative label of being classed '20% disabled'. Generally, participants had a distinctly medicalised view of disability, which included a wheelchair, guide dogs, white sticks and missing limbs. As Goffman (1959) explains, the notion of '*idealized self*' occurs '*when the individual presents himself before others...to incorporate and exemplify the officially credited values of the society*' (p. 45). The pressure of idealized conduct is most clearly seen in marginalised people, who are viewed as 'discredited' (Goffman 1963: 42). Clearly, individuals were framing different constructions of themselves for different situations. Mick's experience was similar to Kirsty's in that initially, he was expecting to 'recover'. Mick, 45, had to leave his job in car manufacturing where he had worked for over 20 years and had been receiving IB for 5 years following the onset of osteo-arthritis. When asked whether he saw himself as disabled, Mick replied:

It's a good question...I see meself as I was but with sort of a painful condition but not as a disabled person, even though I am. Sounds mad but your identity from being an able bodied person, running around cracking jokes and being a normal member of society to suddenly you've got something wrong with ya it does take a lot to contend with, it does.

Goffman (1963: 47) further explains that the emphasis on idealized, normative identity and conduct limits the ability of the 'discredited' individual to achieve full acceptance by the population that he or she is forced to be engaged in – as is the case for Kirsty and others here. Mick's case study is a story in progress that exemplifies '*the act of constructing a longitudinal version of self*' (Bruner 1990: 120). Caroline, 46, had been receiving IB for 5 years due to epileptic-style fits but currently remained undiagnosed. She believed that the medics she had dealt with did not believe her to be genuine: '*I get the impression that they thought I was pretending to be ill*'. Caroline continued in her narrative:

To somebody who doesn't know me, I just look like a normal person...someone who's in a wheelchair or who's been injured in some way y'know if they've only got one arm or one leg, if someone is blind they've got a guide dog or white stick you can tell they're not well. Other people might think well what's wrong with her for her to get that (IB).

Further, as Charmaz (1983) remarks, when the patient does not display any external signs of illness and tests do not show abnormal results, a doctor may regard the patient as someone who is simulating illness or is mentally ill.

The dominant discourse found in the narratives failed to recognise disability as a desired differentness, which can be core to an individual's identity. The only occasion the identity of 'disabled' was accepted was in instances where people were required to class themselves as disabled for official reasons, such as when claiming for certain benefits or applying for a disabled car parking badge. As Kirsty states below:

I really don't like referring to myself as disabled I must admit, I don't but I am and y'know when it comes to official things I will use it. In every day conversation I always refer to it as an injury, but that implies it'll get better and then you have to go into the whole spiel of when people question you.

Throughout her narrative, Kirsty resisted the label of disabled and frequently expressed her desire to lead 'something of a normal life'. Kirsty's performance suggested how she wanted to be known, her 'preferred' self—a normal woman with an injury, thus ascribing to her 'idealized self' (Goffman 1959). Being confronted by a new identity and label of 'disabled' was something that was particularly hard for most participants, yet there was an underlying opinion that portraying a disabled identity would be beneficial when it came to undergoing a medical assessment. The implications could have a negative effect on a person's future chances of seeking employment or training, as they have had to accept the label of 'disabled' for such a length of time. For Jacqui, 50, initially the departure from work as a result of back pain to begin receiving IB was a 'welcome relief' due to her health problems; however, after receiving sickness benefits for over five years, Jacqui said: *'I don't think you have any freedom mentally from it, you're claiming that and it just makes you feel more disabled than you actually are'*.

Hiding identities

Concealing identities and controlling information meant not only deciding who can be given information about their illness, but also how much and what information they would be given, thereby employing a form of stigma management (Goffman 1963). Just as there was an avoidance of accepting the term 'disabled', the stigma of receiving sickness benefits could be so overwhelming that people refused to admit they were

receiving it. In some cases, interviewees refused to reveal their 'claimant identity' to close family and friends, and would even avoid social situations to avoid being asked the question: 'What do you do?' Sarah, a 52 year old who had received IB for 15 years as a result of mental health problems and physical health problems including arthritis and Reynaud's syndrome, described how receiving sickness benefits is highly stigmatising:

I make any excuse to not to go a party, not that I'm invited to many but at church it might be someone's Golden wedding anniversary and if I go and there's people I don't know and they ask me what I do, what do you think I say? I say 'I'm a piece of shit' What else do they want me to say? I say 'I'm one of the dregs of society, I'm one of the ones wasting your tax'.

Comparable findings were reported by de Wolfe (2012: 9) in her study of people with myalgic encephalomyelitis (ME) who were receiving sickness benefits. Nine of her 23 respondents also reported concealing their status as claimant from friends and neighbours; this could be related to being a claimant, not working (as opposed to being a claimant *per se*), or as a result of the belief that, as ME patients, they would be particularly liable to be regarded as scroungers. Sandra's story is an especially clear example of the stigma experienced as a result of being on IB. Following a car accident which led to back problems and severe depression, Sandra had claimed IB for 13 years but nobody other than her husband and the relevant authorities know about it. Sandra said:

She'll (her sister) say 'You must be able to get this' and I'll just sort of change the subject cos I am so ashamed, I really am ashamed. To be honest it's like a rope around your neck, it's horrible that I'm not earning my own money - it's dreadful.

Asbring and Narvanen (2002) studied women with chronic fatigue syndrome (CFS) and fibromyalgia and found that they, too, concealed their sick identity and shied away from friends, family and others who may have previously reacted negatively towards them. However, adopting an identity of appearing to manage can be problematic when thinking about welfare reform. People may fail to sustain such a display at benefits assessments, and, to their detriment, slip into a more customary mode of being able to manage (Donnison and Whitehead 2009: 22). Also, the refusal to admit their benefit status can seek to further isolate people from

supportive family networks, thus increasing the pressure of living with chronic illness or a disability (Garthwaite, forthcoming, 2014).

Validating illness

‘Looking ill’ and appearing to be genuine was a theme that was continuous throughout the interviews; perhaps unsurprising given the continued questioning of sick and disabled people from the government, the media and the wider public (Garthwaite 2011). Mick spoke of how ‘visually’ it was important for him to prove his condition was genuine when he attended a school governor’s event:

I worried if they’d think I was genuine. I remember one of the awards nights [with the school governors] and I showed them me scar on me knee and I felt that was important, I know it sounds crazy but I’m not in a wheelchair or anything so to show them that scar visually...I dunno in me own mind that was important and I’m well known in the community as well and it does bother us wondering if people think I’m genuine or not it’s crazy.

As Charmaz (1983: 181) points out: ‘Although not all chronically ill persons suffer the visible impairments readily resulting in stigmatized identities, many suffer discreditation related to their decreased and now marginal participation in the normal’. In such instances, other identities could be taken on, such as carer, parent or member of staff, which took their mind off their illness, made them feel ‘needed’ and motivated them to keep going. This allowed people to suspend their illness identity temporarily, but once these roles disappeared they returned to an ill state; a finding also reported by Millward *et al.* (2005). Providing legitimacy to their illness narratives was an essential part of daily life for participants. Kirsty described the enacted stigma she experienced at having to persuade her GP to take her pain seriously, which left her with immense frustration:

It took a long time to get referred to see a pain specialist cos my GP kept thinking it was whiplash and saying it would ease. It wasn’t till I had a bit of a meltdown with her and said ‘Look, I’m sick of people telling me I shouldn’t be in pain, please just see why I am rather than telling me it shouldn’t be happening’. With chronic pain they question you - if I was missing a leg not a problem cos they can see it but chronic pain, it’s subjective.

Newton *et al.* (2010) observe that the experience of being disbelieved is stigmatising. The discourse ingrained in government rhetoric and the media encourages others to perceive many sick and disabled benefits recipients as fraudulent and suggests individuals should be disbelieved; despite the fact that fraud levels are a mere 0.5% according to DWP (2011) statistics. Fred, 53, had been receiving IB for over eight years. He had been in the Army and ‘*worked all of his life*’ until polyarthritis set in throughout his body. Fred spoke of the stigma he felt due to being on sickness benefits which was largely related to a particular moment:

God, definitely it does pray on you, he used to call us lazy...the sick parade...I think people of my generation there is a definite stigma attached to being on Incapacity [Benefit]. Because of the stigma from the Army, I shouldn't be down sick. It's that damn mindset and I've spent the last twenty odd years trying to break it. If you are on it, you're a scrounger. It doesn't matter if you've worked for the past 20 years then – bang! – it's scrounger and this flaming stigma. People find out you're on Incapacity Benefit and you just get looked at as through they're scraping you off the bottom of your shoe.

However, life on long-term IB was not always experienced as being so problematic. The following section highlights how the pursuit of aspirations can represent a positive identity shift for long-term IB recipients.

Pursuing aspirations

Negotiating illness does not necessarily result in only negative ‘biographical disruption’. Some studies (Ware and Kleinman 1992) have focused on the social consequences of illness and the strategies developed while coping with health problems. According to Ware and Kleinman (1992), illness can be a catalyst for change in social life, with 50% of their sample declaring the illness experience, although painful, to be ultimately positive. For Asbring (2001:317), approximately 80% of the women in their study described new insights in terms of illness gains, and nearly half of her sample explicitly stated that their illness experiences had positive aspects such as increased self-respect and personal integrity. They had in some regard transcended their illness experience and created a new and more favourable identity than before. A similar sentiment can be found in the narratives presented here, with identity being perceived in a more positive,

uplifting way. Gradually, Mick was able to adjust his identity and begin to present himself as a foster carer instead:

Thinking about a new career, we'd started fostering in 2005 a year before I left my job and we've had some great social workers and some terrible ones and I thought 'I could do that'. I mean I did my level one course and I got a distinction I was like 'Wow I can do it' cos I'd never studied since leaving school. I was so proud I was in tears literally but I think I'm gonna get a second class degree which for me is absolutely phenomenal. I aspire to better myself; I don't want this to stop me in my tracks.

Equally, Terry, 53, had been receiving IB for 12 years and identified as a 'survivor' when speaking about his experience of bipolar disorder:

The way I look at it I'm a survivor y'know? Many a bloke would have ended up in jail, or dead. I was a drunk as well y'know, I used to drink a lot but I don't drink now, I don't touch the stuff.

As Mick and Terry's narratives show, meanings of life events are not fixed or constant, but evolve, influenced by subsequent life events, as Mishler (1995: 5) observes: 'As we access and make sense of events and experiences in our pasts and how they are related to our current selves, we change their meanings' - ends lead to beginnings (Mishler 2000).

Discussion

Identity has been much discussed in the work of Charmaz in the grounded theory tradition (1983; 1987; 1990; 1991). When considering identity, stigma and the lived experience of sickness benefits recipients, a dual stigma can be identified. Firstly, there is the stigma of being sick or disabled, and secondly, the stigma of receiving welfare benefits. Combined stigma is entirely unrecognised in Goffman's seminal work (1963), and is explored further in the findings presented here. Stigma, Goffman argued, arises during social interaction, when the social identity of an individual is found to be 'spoiled' by attributes that mark him or her as deviant (from the group norm) and as being incapable of fulfilling the role requirements of that or other social interactions. For Scambler (2006: 442), while Goffman's contribution retains its theoretical insight and subtlety, it is possible to move beyond what Goffman was saying in his work on stigma and the presentation of self (1959). What is notably absent from Goffman's account of the structure of interaction is the causal input of social structures

like class, gender, ethnicity and so on (Scambler 2006). Goffman's (1963: 41) work highlights how stigma impacts upon 'discredited' individuals – here, sickness benefits recipients – which can lead to consequences for identity formation and reformation.

Secondly, narrating a life on sickness benefits involved a series of identity struggles and considerations that were absent prior to becoming 'incapacitated', especially true when discussing the acceptance or rejection of a disabled identity. Charmaz (2002: 310) notes how some people refuse to take a problematic situation and identify themselves with it as, by giving voice to suffering, people make it theirs and not everyone wishes to do that. Over the years, the disability movement has criticised the 'personal tragedy' view of illness and disability that has been taken by medical sociologists, particularly in relation to embodiment and impairment (G. Williams 1996, S.J. Williams 1999). The rise of the social model of disability has provided a significant challenge to the way academics, practitioners, researchers and policy makers conceptualise the 'problem' of disability (Oliver 1990; Swain *et al.* 1993; Barnes *et al.* 1999). These debates provide a useful context to understanding why participants in the present study were reluctant to adopt a label of 'disabled' or having a disability; disability was perceived as bringing with it an unexpected permanence, whilst many people had hoped their health would improve. Participants saw themselves as both struggling against illness and struggling to maintain their sense of identity. Yet in certain instances, such as having to attend a WCA or when applying for official assistance such as DLA, people felt they had to present themselves 'on their worst days' and portray themselves as being as ill as possible, thus adopting a 'disabled role'. Adopting this role can be problematic as in doing so, being labelled disabled could inhibit peoples' likelihood to return to work in the future and could have a negative impact upon their identity, as the findings presented here have shown. As people shy away from accepting the label of 'disabled', they also risk missing out on benefits that they are entitled to because they dislike the language and terminology surrounding the benefit (Garthwaite 2014).

Thirdly, although the categories of constructing new dimensions of self, validating illness, and pursuing aspirations were separated for analytical purposes earlier, they are not mutually exclusive. Achieving a positive identity was not disassociated from experiencing stigma. All of those who spoke of having a positive identity understood and experienced the stigma of being a long-term sickness benefits recipient - inadequate

amounts of money, coupled with having to be constantly investigated and prove oneself means that the act of being a recipient carried with it a certain level of stigma. Charmaz (1983: 168) observed how participants in her study experienced *'former self-images crumbling away without a simultaneous development of equally valued new ones'*. Findings indicate that *'equally valued'* new identities could be formed for long-term sickness benefits recipients. There are no common themes in the chronic health conditions that can explain why some people narrated a positive identity and others did not. Mick and Terry had been receiving IB for varying lengths of time – 5 and 12 years respectively - showing that length of time with an illness or disability did not distinguish those who constructed positive meanings compared with those who saw nothing but stigma and shame. The pursuit of new, positive identities can be linked to wanting to fulfil familial responsibilities – certainly a defining reason for Mick who stated: *'I didn't wanna give up and I feel strongly that I'm a role model to me children. I didn't wanna be sitting around watching daytime TV'*. As Charmaz (1991: vii) explains, *'chronic illness often crystallizes vital lessons about living'* – clearly the case for Mick who sought to pursue ambitions of becoming a foster carer when he lost his job due to his ongoing health problems. For Terry, the eventual acquisition of a diagnosis for bipolar disorder made him feel *'relieved'* as he now had a name for the condition he had battled since he was a teenager, and the positive consequences of receiving a diagnosis outweighed the negative ones. Charmaz (1994: 277) explains how in her study of chronically ill men, participants sought to make illness and disability meaningful, to recast them into something through which positive identification could be made – as both Mick and Terry have done, primarily founding their preferred identities in action (Charmaz 1994: 284).

Finally, the main implications of the findings suggest that drawing attention to the stigma faced by long-term sickness benefits recipients is crucial. Goffman (1968: 4) defines three classes of stigma, the second of which is most relevant for participants here. Stigma is explained as:

Blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment...unemployment, suicidal attempts, and radical political behaviour.

In the UK, recent policy rhetoric has been accompanied by an increased focus upon individual characteristics and the behaviour of benefits recipients, with the binary between 'deserving' and 'undeserving' benefits recipients now including sick and disabled people, leading to stigma and shame (Bambra 2008; Bambra and Smith 2010; Garthwaite 2011; 2014; Patrick 2011). In order to confront such stigma, the idea that welfare payments are nothing more than a drain on the economy and wider society must be challenged. Instead, they should be seen both as '*an indicator of collective social responsibility and social justice*' (Barnes 2003: 14) and as increasing the spending power within the economy. For example, low-income households spend most of their money within local economies, and disabled people are particularly reliant on labour-intensive services, thereby generating employment. Furthermore, as Williams (2010: 199) observes, chronic illness and disability create the need for many types of work, such as emotional work, biographical work, and illness work, yet these categories are often disregarded as they do not fit neatly within an economic model of production of services and goods (Barnes and Mercer 2005; Corbin and Strauss 1985). The changing nature of welfare policy in the UK represents further challenges for long-term sickness benefits recipients (Garthwaite 2014; Garthwaite *et al.* 2014), not only in terms of ongoing stigma but also the threat of benefits being taken away following reassessment. From April 2013, new and existing DLA claimants will be required to undergo a medical assessment to determine their entitlement, with people in receipt of DLA being transferred to PIP by 2016. From October 2013, the introduction of Universal Credit (UC) will herald further changes for sick and disabled benefits recipients, gradually replacing means-tested benefits for working age claimants, including ESA (income-related) and Housing Benefit. The forthcoming changes will pose further threats to the identity construction and stigma negotiation faced by many sick and disabled people.

Conclusion

Much of the debate about incapacity is focused in a rather narrow and instrumental way on the relationship between ill-health, disability and work. However, incapacity is something that can be seen within a number of different fields of sociological activity: social inequalities in health, the deserving/undeserving binary, disability studies, and the welfare state. The findings presented here offer valuable insights into the lived experience of long-term sickness benefits recipients, as welfare reform continues to affect the lives of sick and disabled people in the UK. The term 'incapacity' can include many realities, including a rejection of a disabled identity, coupled with a reluctance to claim for benefits as a result of stigma and shame. Neither does

'incapacity' reflect the positive outcomes that could arise following a transition onto long-term sickness benefits; in certain instances, the transition can lead to the achievement of new, positive identities that can help to challenge existing negative stereotypes of sick and disabled benefits recipients.

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